

Integrating renal and palliative care project: a nurse-led initiative

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Abstract

Renal nurses working in dialysis settings in Australian regional and rural locations face challenges in facilitating advance care planning (ACP) and providing quality physical and psychological symptom care at the end of life (EOL) for a growing population of older and sicker people with end-stage kidney disease (ESKD).

Following concerns raised by patients, families, renal and palliative care nurses early in 2009 in one regional setting, gaps in service delivery were identified. These identified gaps were supported by an emerging literature that identified the need for integrated, palliative, supportive care earlier in the disease trajectory. This care, provided on a needs basis, incorporates ACP, and identifies and addresses complex symptom and psychological issues to improve quality of life (QOL) and planning EOL care for patients and their families/carers. This approach to care, now called renal supportive care, is in varying stages of implementation across Australia for all renal patients, predominantly in metropolitan centres.

With limited financial resources, a successful multi-professional collaboration and coordinated approach was established in January 2009 in Ballarat, a large regional setting in Victoria. An implementation framework was developed, addressing the continuum of care from pre-dialysis to withdrawal/cessation from renal replacement therapy (RRT), with an integrated palliative supportive approach during active treatment or EOL care.

This project has provided a step forward in improving confidence and responsibility for palliative care by renal nurses working in dialysis settings, helping them to address the challenges faced in evaluating symptom burden, facilitating ACP and delivery of quality EOL care for patients, their families and carers with ESKD.

Keywords

Dialysis, palliative care, nurses, end of life, integration, supportive care.

Introduction

In Australia, the population experiencing end-stage kidney disease (ESKD) is increasing with the 65–69 and 75–79 year group showing the largest increased rates for acceptance for renal replacement therapy (RRT) (Grace, Hurst, & McDonald, 2012). Over the past two decades there has been an increased geographical distribution of centres providing support for people with ESKD, often in regional and rural settings that have limited access to specialist multidisciplinary expertise

(May, 2013). Within this context, renal nurses working in dialysis settings in regional and rural areas can face challenges in managing complex physical and psychological symptom burden, facilitating advance care planning (ACP) and delivery of quality care at the end of life (EOL).

One response to this challenge was the development and implementation of a nurse led integrated renal and palliative care framework in a regional Victorian setting. The framework was designed across the continuum of care for ESKD,

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from pre-dialysis assessment, with an integrated, palliative, supportive approach with people actively dialysing. The continuum of care extended to a post-dialysis EOL setting following cessation of RRT. This approach to care, now called renal supportive care, is in varying stages of implementation throughout Australian renal services, predominantly in metropolitan centres (Josland, Brennan, Anatsiou, & Brown, 2012). This paper explores relevant literature, describes the development of the framework and implementation of the integrated renal and palliative care framework and discusses implications for further research.

Background

Internationally it is recognised that the increasingly older population with ESKD present with an accompanying array of co-morbid conditions, as well as frequently having unrecognised and untreated high symptom burden and correspondingly high mortality rates (Murtagh, Addington-Hall, & Higginson, 2011). This population presents new challenges for health care services, with the need for palliation of complex symptoms, facilitating ACP with planning for EOL care. Globally, over the past two decades a shift has occurred in renal care, from a limited focus on longer survival, to more attention on quality of life (QOL) for people with ESKD, as a way of addressing the changing demographics (Cohen, Moss, Weisbord, & Germain, 2006; Farrington, & Warwick, 2011). This has resulted in greater recognition of the importance of palliative care across the trajectory of chronic kidney disease (CKD)/ESKD for all patients, not just the elderly and frail. Kane, Vinen and Murtagh (2013) identify multidisciplinary, cross-organisational collaboration as central to address the complex care needs for all individuals with ESKD, especially those in the community.

The notion of palliative care is often associated with supportive interventions related to death and dying. While there is limited consensus on a precise definition, Pastrana, Junger, Ostgathe, Elsner, and Radbruch (2008) suggest there is broad agreement about palliation being more than an emphasis on death and dying; it focuses on QOL as a goal of palliative care using multidisciplinary practices and the inclusion of family. Integrated, palliative, supportive care early in the disease trajectory can facilitate ACP, identification and management of symptoms, the provision of support for psychological issues to improve QOL and the planning around EOL care needs (Brown, & Crail, 2013; Davison, 2011; Fassett, Robertson, Mace, Youl, Challenor, & Bull, 2011; Kidney EOL Coalition, 2013; Moss, 2003; Moustakas, Bennett, Nicholson, & Tranter, 2012; NHS Kidney Care, 2008; Tumura, & Cohen, 2010).

In early 2009 a number of reports were received by the Community Palliative Care Service in our region about palliation for people with ESKD. Both renal nurses and families/carers raised issues that included referral pathways, nurse confidence

and skill, as well as the use of ACP. Late referrals to palliative care were reported as resulting in a lack of planning, education on medication use and support for families caring for dying patients at home, following cessation of dialysis. There were concerns about renal nurses feeling inadequate in assessing and planning for patients withdrawing from dialysis and planning EOL care. There was little in place to support the use of ACP. There were also reports of renal nurses feeling they had no voice to influence or effect referrals to the Community Palliative Care Services in our region.

With the support from a small community grant (\$3000) a specialist palliative care nurse, in collaboration with renal nurses working in the dialysis unit, undertook preliminary work to establish a project to identify and address palliative care support within the dialysis unit. Following discussion with the managers of the dialysis unit and Community Palliative Care Service, a nurse-led working group was formed. Initially, membership was constituted of nurses from both services and later expanded to include a social worker and both the renal and palliative care physicians. The project worker undertook a literature review about EOL care pathways for people with ESKD and networked with other services exploring EOL pathways for people with ESKD. The literature review provided some direction for the working group and focused on haemodialysis as the key area of interest because this was the major emphasis of service delivery in the region.

Literature review

The key focus of the literature review was the current approaches and guidelines available for integrating palliation in ESKD, as well as challenges renal nurses face in integrating palliative care in their practice.

In early 2009 when this project began, there were few tangible examples of routine implementation of integrated palliative supportive care in Australian renal settings. Renal supportive care service models and renal palliative care clinical networks have since been established nationwide (Josland *et al.* 2012; Victorian Renal Supportive Care Initiative, 2013). Australian renal supportive care guidelines have recently been published which support enhanced practice relating to ACPs and EOL care in renal contexts (Brown, & Crail, 2013). There has also been a shift to embed renal supportive care into policy and strategic planning to guide service and system development; for example, the Western Australian Department of Health, "Pathway for Renal Palliative Care Services" (2012) and the Victorian Renal Directions (2013). Kidney Health Australia (KHA) is leading a national education project with plans to include an online renal supportive care education module (Department of Health, 2013b). A joint position statement between Palliative Care Australia (PCA) and KHA has also been launched advocating education and provision of information for renal health professionals about palliative care and renal disease (PCA, 2013).

There is scant literature exploring the challenges for renal nurses caring for people with ESKD patients with whom they are likely to have established long and close relations. Johnson and Bonner (2004) argued that withdrawal from dialysis had a seriously under-recognised and largely invisible impact on renal nurses. The focus of practice for haemodialysis nurses has predominately concentrated on the technical, monitoring and evaluative aspects of dialysis therapy to optimise treatment outcomes for patients with ESKD. The longevity of RRT results in the formation of different types of relationships between dialysis staff, patients and their families/carers, in contrast to the relationships developed in acute, short-term care settings. Consequently, a shift in focus from active treatment to palliation creates challenges for dialysis staff in the planning of EOL care for patients who choose a non-dialytic pathway, patients whose condition deteriorates despite dialysis, or those considering withdrawal of dialysis.

Feldman, Berman, Reid, Roberts, Shengelia, Christianer, Eiss, and Adelman's study of renal health care professionals (2013) examined barriers to symptom management and found participants were often unaware of the magnitude of symptom burden in their patients. Barriers included management and a lack of ownership for assessing and treating symptoms accompanied by a perception that certain symptoms were "untreatable". Caregivers believe in providing relief from suffering but are uncertain about decisions regarding implementation issues (Tong, Cheung, Nair, Tamura, Craig, & Winkelmayer, 2014). To increase clinicians' confidence in engaging in meaningful EOL communication with patients and families, structured guidance, specific advice and practical tools need to be provided (You, & Fowler, 2014).

Studies relating specifically to renal nurses in Spain (Ho, Barber, Hidalgo, & Camps, 2010) and Greece (Zyga, Malliarou, Athanasopoulou, & Sarafis, 2011) reported nurses encountered difficulties in managing EOL care and highlighted the need for education to help nurses develop palliative care skills and knowledge. Similarly in the US, Hopkins, Kott, Pirozzi, Deppoliti, Pond, and Randolph, (2011) showed renal nurses were not comfortable with EOL discussions with patients and families prior to education.

Studies exploring generalist nurses' attitudes and feelings about death and EOL in a number of countries consistently indicate issues with confidence and knowledge about EOL (Proctor, Grealish, Coates, & Sears, 2000; Raudonis, Kyba, & Kinsey, 2002; Gott, Gardiner, Small, Payne, Seamark, Barnes, Halpin, & Ruse, 2009; Zomorodi, & Lynn, 2010). A recent review of literature (Peters *et al.*, 2013) identified death anxiety and personal attitudes towards death and dying may influence the quality of care that nurses provide during the terminal stages of a person's life. This review also identified that short courses about death and dying had positive outcomes for nurses coping with their fears of the reality of deaths.

The review of literature revealed limited evidence about the challenges renal nurses experience in addressing complex symptom management, the delivery of ACP and quality EOL care for patients, their families and carers. Despite renal nurses in dialysis settings being well placed to play a role in facilitating and coordinating patients transitioning from a curative, restorative phase of chronic illness to a palliative, terminal phase, there is some evidence suggesting nurses are not confident in adopting this role. The review suggested the need to support nurses to assist patients, their families and carers to navigate an integrated, palliative, supportive care pathway early in the disease trajectory on a needs basis. It was also evident that support for renal nurses requires specific educational interventions, improved resources and access to collaborative partnerships with expert health professionals.

In light of these findings, the working group aimed to achieve the following objectives:

- To improve collaboration between renal and palliative care providers.
- To integrate palliative supportive care early in the ESKD disease trajectory on a needs basis, including advance care planning.
- To improve outcomes for patients, their families and carers with ESKD at EOL.

The United Kingdom Renal End of Life Framework (NHS, UK, 2008) guided the development of an *Integrated Renal Palliative Care Framework* for implementation in our region. In our setting, renal nursing staff, families and carers had identified the following situations as key areas for service enhancement:

- Patients with advanced chronic kidney disease (ACKD) not commencing dialysis (renal supportive care option);
- Patients deteriorating despite dialysis;
- Patients presenting with dual diagnoses (e.g. cancer); and
- Patients ceasing or withdrawing from dialysis treatment.

The framework was organised across three vertical columns related to phase of RRT: pre-dialysis/no RRT, dialysis, and post-dialysis. In each of these phases, mechanisms for operating within a shared decision model are described and prompts and triggers to support planning and decision making are identified (Figure 1). All phases show the importance of providing information that supports informed consent and shared decision making. Involvement of families/carers through family meetings is highlighted in each phase. The consideration of referral to palliative care at any stage in the trajectory on a needs basis was also emphasised with referral processes refined.

Tools and strategies

Greater prominence of the need for quality, compassionate, patient-centric, supportive care for people with ESKD has led to the recommendations for the use of prognostic scores, QOL assessments and targeted symptom management guidelines (Raj, 2013). Tools and strategies to support practice within this framework include the use of the Patient Outcome Scale Renal version (POS-S Renal) and the development of ACP. Advanced care plans are to be held by patients and relevant health professionals. These tools are briefly described below.

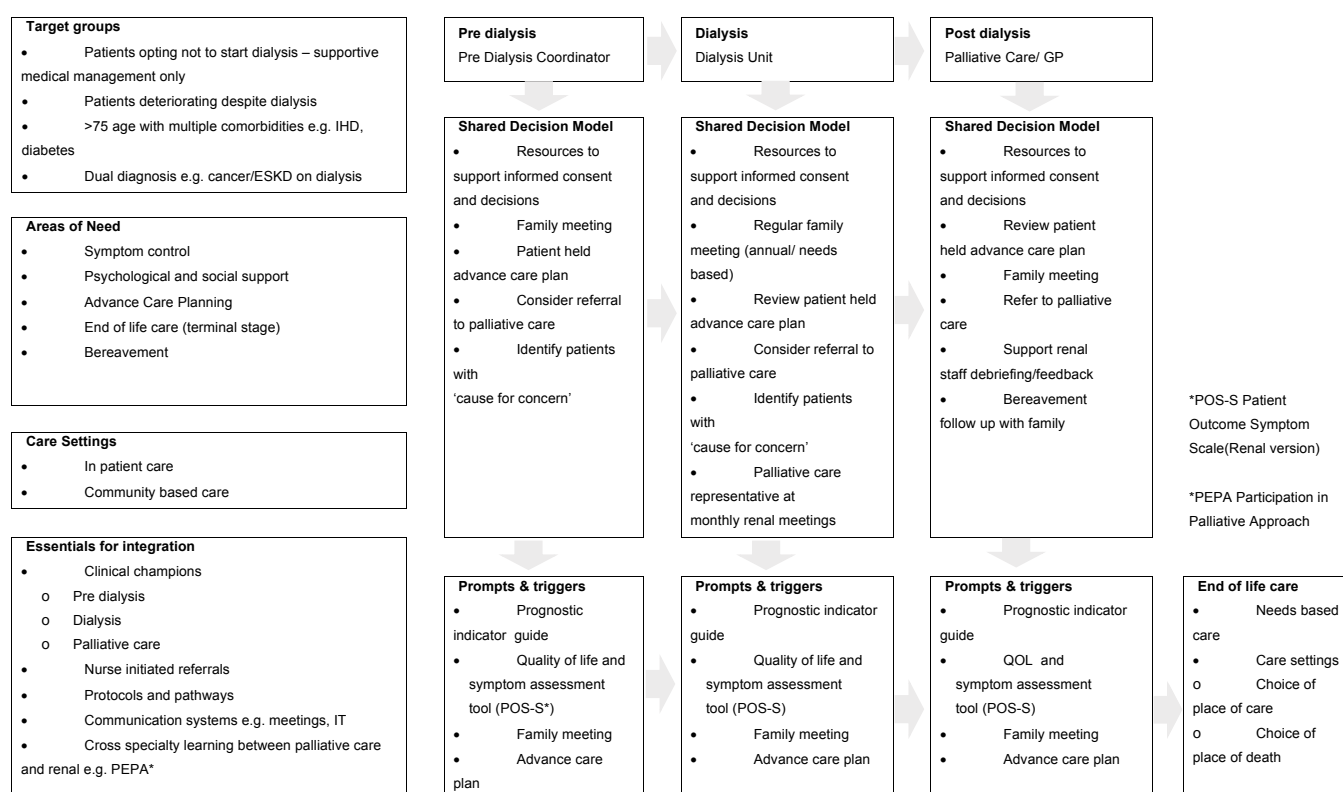
Hearn and Higginson (1999) developed and validated the initial Palliative care Outcome Scale (POS), which has been widely adopted in clinical practice and research. The POS tool has developed over the past 15 years into a family of measures that comprehensively assess symptoms and needs of people with significant chronic illnesses that are life limiting (Bausewein, Le Grice, Simon, & Higginson, 2011). While technically named the Palliative care Outcome Scale, the POS is also referred to as the Patient Outcome Scale, because it is also used in non-palliative care settings. The measure can be completed by patients and/or staff, requiring the respondent to rate physical symptoms, psychological, emotional, spiritual, information and support needs, using a Likert scale where 0 is best and 4 is worst. There is a version available specifically modified for use in populations with kidney disease called the Patient Outcome Scale — Symptoms Renal (POS-S Renal). It is a 17-item scale, which includes disease-specific symptoms. The POS-S (Renal) assessment tool has been internationally recommended as

a useful and clinically effective tool for assessing symptom burden. Using a standardised tool also allows information about symptoms to be collated (Brennan *et al.*, 2013; Murphy, Murtagh, Carey, & Sheerin, 2009). The implementation of this tool is in line with the Palliative Care Australia (PCA) and KHA's Joint Position Statement call for "National implementation of a validated tool to objectively measure the symptom burden associated with ESKD with an associated quality improvement indicator" (PCA, 2013).

ACP is a form of communication where individuals can communicate their values and choices about their future health care decisions to health care professionals, (International Society of Advance Care Planning and End of Life Care (2013). Even though ACP is becoming embedded into Australian health service funding, health care professionals at all levels of organisations will be the key to ensuring the successful implementation of ACP (Gunther-Murphy (2013). The Australian Health Ministers' Advisory Council published a national framework for Advance Care Directives in 2011, which aimed to support greater use of advance care planning in the Australian community. Recently, the Victorian Government developed and launched a new strategy *Advance care planning: have the conversation: A strategy for Victorian health services 2014–2018* to assist health care professionals as they discuss this important issue and ensure the wishes of patients are honoured.

The final prompt strategy in the framework was the use of prognostic indicators to deliver earlier planning and better

Figure 1. Integrating Renal and Palliative Care Project – A Framework for Implementation



coordinated care at EOL. Prognostic indicators are used primarily to recognise the dying (Thomas, 2011). The Gold Standard Framework (GSF) Prognostic Indicator Guidance (4th Edition, October 2011) suggests following three triggers for considering patients to be near EOL. Firstly, applying the intuitive surprise question: Would I be surprised if this patient died within the next six months? The second trigger to consider is the general clinical indicators of decline; for example, decreased performance status and functional ability (such as, in bed 50% of day), co-morbidity, progressive weight loss (>10%) in last six months, advanced unstable disease and serum albumen <25g/l. The third trigger to consider is a specific clinical indicator, for example, people with Stage 4 or 5 CKD whose condition is deteriorating, with difficult physical or psychological symptoms, despite optimal, tolerated RRT (Cohen, Ruthazer, Moss, & Germain, 2010).

Implementation of the framework

A staged approach to implementation was adopted. Firstly, approval of the framework for implementation was gained from the nurse unit manager of the dialysis unit, the executive officer of the Community Palliative Care Service, together with both of the renal and palliative care physicians for adopting the framework. Secondly, clinical champions were identified with a pre-dialysis nurse champion and a dialysis nurse champion selected from the dialysis services, and the post-dialysis champion was a specialist palliative care nurse from the Community Palliative Care Service. These champions met regularly and worked together to positively promote the framework in the regional area.

The local health service implemented an EOL project in 2013 piloting processes within the renal unit. There were three phases to the EOL project including shifting from a Resuscitation plan to a Goals of Care plan where patients are involved in decision making about their health care goals. In addition, a specific management plan was implemented so that people in the last days or hours of life receive consistent, individualised care that involves them and their families/carers in decision making about their care and treatment. Lastly, advanced care plans are now available to those who wish to discuss and document their health care wishes ahead of time.

The POS-S (Renal) assessment tool was introduced to patients in the dialysis unit in June 2012 by the clinical nurse champion. It was offered to be used at the following points in time in a patient's journey: pre-dialysis, six weeks post commencing dialysis, three-monthly while on dialysis, and whenever else there is a perceived need. Anecdotally, indications from the renal nurses suggest that the use of the POS-S (Renal) assessment tool to identify high-scoring symptoms has helped to open up conversations between staff and patients. These nurses report improved confidence in addressing ACP and EOL planning through completing Goals of Care documentation.

The introduction of direct referrals to palliative care services by renal nurses, with patient consent, addressed nurses'

perceptions of having no voice about accessing palliative services. Additionally, a social worker triage process has been established with referrals on a needs basis. Palliative care staff are included in social worker-led family meetings and invited to attend monthly dialysis case meetings.

Education processes

Promoting transference of knowledge, skills and expertise through education was clearly a key strategy for the implementation of the framework. The first goal was to provide education for the champions and staff of the dialysis unit. The clinical champions undertook training in advance care planning through "Respecting patient choices®" program at the Austin Hospital, Victoria. The federal PEPA program (Participant in Experience of the Palliative Approach) funded a placement for the dialysis clinical champion at the Community Palliative Care Service in 2013. Renal nurses in the dialysis unit were provided with education sessions introducing contemporary palliative approaches with the aim of empowering them to engage in using the framework in their practice. Additional education was provided to those nurses in the use of the POS-S (Renal) assessment tool prior to the introduction of the tool to the patients in the dialysis unit.

This project has highlighted an area of need elsewhere in the Grampians region of Victoria. Through partnering with other community-based palliative care services, across the broader geographic region, nurses working in satellite dialysis settings have been given access to education to support the adoption of the integrating renal and palliative care framework in their clinical practice.

Conclusion and recommendations

The main outcomes achieved through the development of an integrated renal palliative care framework included: the introduction of nurse-initiated referrals to palliative care; and the implementation of a shared care model between renal services and palliative care services, including medical and allied health collaboration. Informal feedback from stakeholders suggests improved confidence and ownership of care for renal nurses, assisting them to address the challenges of caring for people with ESKD, their families and carers either opting for a supportive non-dialysis pathway or RRT option. The successful multiprofessional collaborative partnership between the renal and palliative care services continues to support and develop renal nurses' approach to supportive care for their patients.

There is a lack of evidence nationally and internationally exploring or describing renal nurses' perspectives on the challenges of caring for patients with significant symptom burden, the delivery of ACP and planning quality EOL care. In a changing environment, they are increasingly required to discuss difficult and sensitive aspects of care and engage in meaningful EOL communication with patients, their families and carers. Further exploration is required to understand the needs and dilemmas facing renal nurses.

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